

THE GENOME PROJECT AS PUBLIC POLICY*

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ONE OF THE KEY LEGAL CHALLENGES arising from the Human Genome Project is to reduce the potential for genetic discrimination. Genetic-based discrimination could arise in a variety of ways, some of which we see already. The Human Genome Project, by accelerating growth in genetic knowledge, could facilitate genetic discrimination. Thus, it is imperative that we study the potential for genetic discrimination and begin taking steps to prevent it.

Genetic screening in a nontherapeutic setting is widely considered a likely way to identify individuals with atypical genotypes, who then may be subject to differential treatment. Although employment and insurance are examples that come to mind most readily, other third parties also have a considerable interest in whether a currently healthy individual might be likely to develop some debilitating, disabling, costly disease in the future. For example, a medical school admissions committee or residency committee might want to know what the health of an applicant will be in 10 years before making a huge investment in that individual. Knowledge of a parent's future health might be relevant in a child custody dispute or in an adoption proceeding. A mortgage lender might want to know what the health of an applicant is going to be 10 or 20 years from now.

Employment and insurance, however, remain appropriate starting points for discussion. We already have vast experience dealing with employment-based and insurance-based discrimination, and we already have enacted laws to cover these situations. This fact gives us the opportunity to see how the legal system has responded to the problem of health status discrimination. It should be noted at the outset that some of the concerns about employment discrimination based on genetic traits are unique to the United States due to

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our health care system. Much of the genetic-based discrimination already existing is directly related to health insurance “cost containment” and this is the type of discrimination likely to take place in the future.

Genetic-based discrimination also raises a number of problems that do not arise in other forms of disabilities-based discrimination. For example, it is necessary to define what it is to be “diseased.” Is carrying a genetic marker or having some variant polymorphism a disease in the same way that being orthopedically impaired or visually impaired would constitute a disease? Should we treat genetic diseases differently from other diseases? In our attempts to regulate, should we seek to control access by third parties to genetic information or use of the information by third parties?

Another threshold question is what does it mean to “discriminate” in employment and insurance? We already discriminate in various ways, for example, by limiting jobs to individuals based on their experience, education, or prior performance. In employment, however, only invidious discrimination is ethically unacceptable and only some specific forms of invidious discrimination, such as discrimination based on race, national origin, or sex are illegal. We also already discriminate in insurance and employment on the basis of genetics—either in absolute terms, by refusing to insure or employ someone; or in relative terms, by preferring one person over another. This is based largely on the effects of genes. What the Human Genome Project will hasten, and to some extent what we can do already, is to predict which unexpressed genes may at some time in the future lead to gene expression with deleterious consequences.

It is helpful to divide the potential bases of discrimination in employment into four categories based on the timing, manner, and likelihood of gene expression. A caveat is that this is a legal/policy/ethics classification that does not necessarily correspond with scientific genetic classification.

In the first category are currently affected individuals. An example would be individuals afflicted with multiple sclerosis, a relatively common genetic-related disease. Many people with multiple sclerosis are able to work. The issue is whether someone who has multiple sclerosis, with reasonable accommodation, can perform a particular job.

The second category is comprised of individuals who are presymptomatic or possibly presymptomatic for a late-onset genetic disease. Examples would include Huntington’s disease and adult polycystic kidney disease. The reason why there may be no difference between actual carriers and presumed carriers can be seen by looking at the problem from the employer’s perspective. With regard to Huntington’s disease and adult polycystic kidney disease, autosomal-

mal dominant diseases, both a confirmed carrier (with a 100% risk) and a possible carrier (with a 50% risk) have risks that may be viewed by some employers as being unacceptably high, and therefore these employers might discriminate against both classes of individuals.

The third category consists of heterozygote carriers of recessive disorders. Why would an employer want to screen out an individual who is only a heterozygote carrier of cystic fibrosis, Tay-Sachs disease, or similar disorders when that individual is not going to be affected? The answer is that employers may not want to hire someone at increased risk of mating with another heterozygote and having a child with one of these terrible, costly conditions.

The fourth category includes individuals at an increased risk of a multifactorial disease, such as coronary artery disease. The Human Genome Project can be expected to move the science beyond single gene disorders to a wide range of genetically predisposing conditions.

For each of these categories it must be determined whether these individuals are covered by antidiscrimination laws and whether the discrimination, if it exists, is lawful. The *Philadelphia Inquirer* (March 31, 1991) contained a story that illustrates why some employers might be tempted to discriminate. A woman named Janice Bone was a payroll clerk at a company in Wabash, Indiana. She was fired because a urine test was positive for cotinine, a metabolite of nicotine. The urine test detected that she had smoked cigarettes at home. This violated a company policy against smoking on or off the job. Why ban smoking off work? The answer is to save money on health insurance costs. Cigarette smokers are more likely to develop emphysema, lung cancer, heart disease, and other illnesses. On average, they require several hundred dollars a year more in health care than nonsmokers. Today, 6 to 10% of companies refuse to hire people who smoke cigarettes, even if they only smoke at home. Other companies monitor their employees' weight, blood pressure, cholesterol levels, blood sugar, drinking, diet, and hobbies such as motorcycle riding and skydiving. According to John M. Finney, Head of Corporate Health Policies Group, a consulting company: "As health care costs go up, what's justifiable goes up." It seems to me that what is economically justifiable may go up—but not necessarily what is medically justifiable, what is legally justifiable, or what is ethically justifiable.

The reason why companies have been under pressure to engage in increasingly detailed medical screening is directly related to health care expenditures. Expenditures per employee for health care increased from \$1,700 in 1985 to \$3,200 in 1990, and continue to increase 15 to 20% every year. One of

the consequences is that many employers attempt to get high cost health care users out of the pool. And the pool often includes more people than just the employee. Forty-seven percent of all employer health costs go to the treatment of employees' dependents. In a 1989 survey of *Fortune* 400 companies, 15% of responding companies said that they plan to prescreen family members prior to hiring a new employee. This survey confirms the data from anecdotal case studies: An applicant who has a child with cystic fibrosis or an applicant with a spouse on dialysis treatment would have a serious problem getting a job. Therefore, it is a very small jump to say that an applicant who carried the cystic fibrosis gene or an applicant whose spouse carried the gene for kidney disease and is likely to develop a condition needing dialysis in the future would find it difficult to get a job. And if the individual already has a job, it may be virtually impossible to change jobs because many health insurance plans have exclusions for preexisting conditions.

The principal law to address genetic discrimination in employment is the new Americans with Disabilities Act. This is the first comprehensive federal employment discrimination law prohibiting discrimination on the basis of disabilities. It was passed by Congress in July 1990 and will take effect in July 1992 for employers with 25 or more employees and July 1994 for employers with 15 or more employees. It applies to private sector employers and state and local governments. It does not apply to the federal government, although the federal government is covered by comparable provisions of the Rehabilitation Act. Section 102(a) of the Americans with Disabilities Act provides: "No covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment." The definition of disability under the act follows the current three-part definition under the Rehabilitation Act. It is a physical or mental impairment that substantially limits one or more of an individual's major life activities (which includes working), having a record of such an impairment (e.g., having had a heart attack 10 years ago), or being regarded as impaired (even though the individual is not impaired).

The act requires employers to make reasonable accommodations for individuals with disabilities to permit them to work. Most accommodations, such as making facilities accessible and making minor changes in work practices, are relatively inexpensive. Provision of qualified readers or interpreters for blind workers or deaf workers, however, are much more expensive. An accommodation will not be required if it would result in undue hardship to the

employer. This is based on several factors, such as the size and profitability of the employer and the nature of the accommodation.

The medical examination provisions of the act are extremely important. Traditional pre-employment medical examinations and questionnaires are now illegal. An employer may only ask applicants about their ability to perform job-related activities, such as whether they can walk up steps, drive a car, or lift boxes. An employer may not ask if the applicant has epilepsy, diabetes, hypertension, or other specific medical conditions. After a conditional offer of employment, an employer may require an "employment entrance examination." On February 28, 1991 the Equal Employment Opportunity Commission issued proposed regulations to implement the act, which said that these examinations need not be job-related. In my view, this interpretation not only is wrong, but it facilitates discrimination for a number of reasons.

First, currently, job applicants and conditional offerees have no right to know what medical tests are being performed. There is no physician/patient relationship and an employer can make consent to a medical test, such as a blood test, a valid condition of employment. Nevertheless, there is no right to know what specific blood tests are being done, there is no right to know the results of those tests, and there is no right to know the reason for a negative hiring decision based on a medical test or for any other reason. Thus, a conditional offeree would not even know if there were reliance on a non-job-related medical test. That is why it is important to prohibit the use of non-job-related tests in the first place.

Second, the Americans with Disabilities Act was intended not only to prohibit discrimination against individuals with disabilities, but it was also designed to promote autonomy and to protect the privacy and dignity of individuals with disabilities. Individuals should not have to reveal personal medical information that is not relevant and related to their jobs. Non-disclosure of medical information unrelated to employment is essential to prevent the stigmatization that often accompanies genetic disorders.

The act also provides that non-job-related medical examinations may be given to current employees only if they are voluntary. With regard to health insurance, employers may not deny health insurance coverage completely to an individual based on the individual's diagnosis or disability. Nevertheless, limitations may be placed on reimbursements for particular procedures to the extent otherwise permitted by law. For example, an employer could not refuse to provide insurance to people with a history of cancer because people with a history of cancer get colds and influenza and break their legs and need

all sorts of non-cancer medical care. An employer could, however, to the extent permitted by state insurance law, refuse to extend health insurance coverage for pre-existing conditions, which could include cancer or other diseases.

Section 102(b)(4) of the act is relevant to genetic discrimination. It provides: "The term discriminate includes excluding or otherwise denying equal jobs or benefits to a qualified individual because of the known disability of an individual with whom the qualified individual is known to have a relationship or association." This provision was included in the act because of reports of discrimination against people with a friend or roommate who had AIDS. But §102(b)(4) also would prohibit discrimination against an individual who had a child who was sick or whose spouse was sick or because some other dependent or associate suffered from a genetic or other disease.

It is important to consider how wide-scale, genetic-based employment discrimination could occur. In my view, for the foreseeable future employers are unlikely to embark upon massive screening either for occupationally-related genetic conditions or for non-occupationally-related genetic conditions. What is more likely to happen is for employers to refuse to hire people based on two sets of medical records. First is lawfully obtained, job-related medical records. For example, suppose that a conditional offeree is being evaluated for a job at NYNEX, which involves climbing telephone poles. If the individual had a knee operation last year, the employer might legitimately want to know what the surgeon found when the operation took place. The individual would sign a form releasing his medical records to NYNEX. When the hospital and surgeon release the medical records, however, they are not going to spend hours purging all of the other non-job-related, non-knee-related medical information from their files. They are going to send the entire file, which may contain much information irrelevant to the job, possibly including genetic information.

The second way that genetic information may be disclosed to an employer is through medical claims. For example, suppose an individual who works for a self-insured company goes to the doctor for any kind of medical treatment and the doctor's bill is \$100. Customarily, the doctor will send a \$100 bill to the patient's employer, but along with the bill will be a statement or coded form indicating what medical services were rendered. The services may have involved things such as psychiatric care, a vasectomy, alcoholism treatment, or genetic disease treatment. If we are going to try to protect the confidentiality of medical records, including genetic records, we need to focus on both the releases of raw medical files and the confidentiality of medical claims

information. At the present time, it is not economically feasible (even if it were technologically feasible) to screen asymptomatic individuals for a wide range of rare genetic conditions.

In conclusion, to the extent that the Human Genome Project increases genetic information about individuals, then we must recognize the possibility that the information could lead to genetic discrimination. Statutory enactments such as the Americans with Disabilities Act can help, but cannot be expected to prevent all discrimination when there are such strong economic incentives to discriminate. Consequently, we must carefully consider policies in both the public and private sectors to minimize the incentives and opportunities for this form of invidious discrimination.